

**The Importance of Mandatory Laboratory Reporting  
in Assessing the Economic Impact  
of Lyme Disease in Connecticut**

**Statement**

**by**

**Yvonne Bokhour  
Master's Candidate  
Health Advocacy Program, Sarah Lawrence College  
and Co-facilitator  
Wilton Lyme Disease Support Group  
Yvonne@Bokhour.com**

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## **Oral Testimony**

### **Introduction**

Good afternoon Madame Chair and members of the Committee. My name is Yvonne Bokhour and I am a graduate student studying Health Advocacy at Sarah Lawrence College. For the past 9 years, I have co-facilitated the Wilton Lyme Disease Support Group. I am here today in support of Bill Number 5747.

More than 700 patients have shared their stories at the Support Group since 1998. Their heartbreak, and my personal encounter with Lyme disease (LD), led me to graduate school. My current research, contained in my written testimony, concerns the economic impact of Lyme disease, particularly the financial hardships imposed by misdiagnosed and under-treated Lyme. This afternoon, I will highlight a few key findings, which provide dramatic support for the importance of accurate reporting.

Over the years, trends have emerged in patient narratives. Most arrive at our group with late-stage Lyme that has advanced due to misdiagnosis or inadequate treatment. Some have been infected more than once. Co-infection is increasingly common. Multiple family members may be stricken together. Patients' lives may be thrown into turmoil by the intensity of their illness. In addition, they may be overcome by financial burdens. Economic ramifications extend beyond individuals to schools, employers, insurers and government.

Accurate case reports are essential to assess Lyme's economic and public health impact. Numerous studies published before and after Connecticut eliminated mandatory lab reporting have demonstrated that official case reports of Lyme disease represent only 10 to 20% of diagnosed cases.<sup>1, 2, 3, 4, 5, 6</sup>

Although Lyme is the most common vector-borne disease in the United States, economic research has been limited.<sup>7,8</sup> The latest study was published in 2006 by the Centers for Disease Control (CDC).<sup>9</sup> Let's look at their numbers, which provide a pointed glimpse into the importance of accurate case reports. The calculations I will present were made under the direction of Peter S. Arno, Professor of Health Economics at Sarah Lawrence and Director, Division of Public Health & Policy Research in the Department of Epidemiology and Population Health at Montefiore Medical Center.

The CDC calculated that "in general, a LD patient (clinically defined early or late stage) costs \$2,970 in direct medical costs plus \$5,202 in indirect medical costs, nonmedical costs, and productivity losses."<sup>10</sup> These costs understate those of support group attendees, whose expenses are generally higher. But if we apply these conservative numbers, which total \$8,172 per case, to CT case reports in 2005, which total 1,810 cases,<sup>11</sup> the economic impact amounts to nearly \$15 million dollars in that year (\$14,791,320).

Let us take our calculations a step further. If we assume the official number of case reports in 2005, or 1,810, represents 15% of diagnosed cases (a conservative mid-range estimate) the total number of diagnosed Lyme disease cases in 2005 would have been 12,067 not 1,810. If we multiply the costs per case (\$8,172) by the total number of cases (12,067), the economic impact jumps to nearly \$99 million dollars (\$98,608,800). The difference in economic terms between roughly 1,800 cases and 12,000 cases is nearly \$84 million dollars. It would be even higher if we took inflation into account. And of course, the 1,800 cases officially listed are much less than they would have been had labs been reporting. In fact, let's use the same approach to assess 2002, the last year before mandatory lab reporting was eliminated. If we again assume official case numbers represent 15% of diagnosed cases, the

4,631 cases reported that year<sup>12</sup> really reflect 30,000 (30,873) cases of Lyme in CT. In economic terms this would have generated costs of more than \$250 million dollars.

This dramatic economic impact is based on conservative numbers that do not include costs associated with misdiagnosis, under-treatment, repeat infection, co-infection, number of household members affected, insurance claim denials and expenses incurred by employers and schools. It is hidden by poor reporting in general and made worse by the lack of mandatory reporting specifically. The fact that these costs are hidden does not mean they are not real to patients, their families or society at large.

Until researchers resolve numerous diagnostic and treatment dilemmas, patients will continue to battle symptoms that affect not only their personal well-being, but the financial security of their families and the economic fabric of their towns and states. Hundreds of patients seen at the Support Group testify to the importance of accurate reporting and additional economic research. Bill Number 5747 corrects a serious misstep by the State of Connecticut and will help move us forward to more fairly and accurately deal with the Lyme disease epidemic here and across the country.

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- <sup>1</sup> Zhang Z, Meltzer MI, Pena CA, Hopkins AB, Wroth L, Fix AD. "Economic Impact of Lyme disease." *Emerging Infectious Diseases*, 2006; 12 (4):653-660.
- <sup>2</sup> Centers for Disease Control and Prevention. "Lyme disease—United States, 2000." *MMWR Morb Mortal Wkly Rep*. 2002; 51; 29-31.
- <sup>3</sup> Meek JI, Roberts CL, Smith EV Jr, Carter ML. "Underreporting of Lyme disease by Connecticut Physicians, 1992." *Journal Public Health Management Practice* 1996; 2: 61-5.
- <sup>4</sup> Coyle, BS, Strickland GT, Liang YY, Pena C, McCarter R, Israel E. "Public impact of Lyme disease in Maryland." *J Infect Dis* 1996; 173: 1260-2.
- <sup>5</sup> Millward Brown. "Lyme Disease Research Study Conducted for the Wilton Task Force on Lyme Disease and Other Tick-Borne Illnesses, Inc." April 2001.
- <sup>6</sup> Connecticut Agricultural Experiment Station. *Tick Management Handbook*. 2004. Available at [www.cdc.gov](http://www.cdc.gov).
- <sup>7</sup> Centers for Disease Control and Prevention. *MMWR*, 51, No. 2 (18 January 2002): 29-31.
- <sup>8</sup> Zhang Z, Meltzer MI, Pena CA, Hopkins AB, Wroth L, Fix AD. "Economic Impact of Lyme disease." *Emerging Infectious Diseases*, 2006; 12 (4):653-660.
- <sup>9</sup> Zhang Z, Meltzer MI, Pena CA, Hopkins AB, Wroth L, Fix AD. "Economic Impact of Lyme disease." *Emerging Infectious Diseases*, 2006; 12 (4):653-660.
- <sup>10</sup> Zhang Z, Meltzer MI, Pena CA, Hopkins AB, Wroth L, Fix AD. "Economic Impact of Lyme disease." *Emerging Infectious Diseases*, 2006; 12 (4):653-660.
- <sup>11</sup> Centers for Disease Control. "Reported Lyme Disease Cases By State, 1993-2005." Available at: [http://www.cdc.gov/ncidod/dvbid/lyme/ld\\_rptdLymeCasesbyState.htm](http://www.cdc.gov/ncidod/dvbid/lyme/ld_rptdLymeCasesbyState.htm). Accessed 25 Feb 2007.
- <sup>12</sup> Centers for Disease Control. "Reported Lyme Disease Cases By State, 1993-2005." Available at: [http://www.cdc.gov/ncidod/dvbid/lyme/ld\\_rptdLymeCasesbyState.htm](http://www.cdc.gov/ncidod/dvbid/lyme/ld_rptdLymeCasesbyState.htm). Accessed 25 Feb 2007.

**Economic Costs, Reported and Estimated Cases of Lyme Disease  
Connecticut, 2005 & 2002**

	2005		2005		2005		2005	
	Actual Reported Cases**	Estimated Cases Reported	10% Low	20% High	Estimated Cases Reported	15% Medium	Estimated Cases Reported	20% High
2005 Reported Cases	1,810		9,050		18,100		12,067	
Costs Per Case*								
Direct Medical	\$2,970	\$ 5,375,700	\$ 26,878,500	\$ 53,757,000	\$ 35,838,000			
Indirect	\$5,202	\$ 9,415,620	\$ 47,078,100	\$ 94,156,200	\$ 62,770,800			
Total	\$8,172	\$ 14,791,320	\$ 73,956,600	\$ 147,913,200	\$ 98,608,800			

	2002		2002		2002		2002	
	Actual Reported Cases**	Estimated Cases Reported	10% Low	20% High	Estimated Cases Reported	15% Medium	Estimated Cases Reported	20% High
2002 Cases	4631		23,155		46,310		30,873	
Costs Per Case*								
Direct Medical	\$2,970	\$ 13,754,070	\$ 68,770,350	\$ 137,540,700	\$ 91,693,800			
Indirect	\$5,202	\$ 24,090,462	\$ 120,452,310	\$ 240,904,620	\$ 160,603,080			
Total	\$8,172	\$ 37,844,532	\$ 189,222,660	\$ 378,445,320	\$ 252,296,880			
Difference between 2002 and 2005								
								\$ 153,698,080

\*Zhang Z, Meltzer MI, Pena CA, Hopkins AB, Wroth L, Fix AD. Emerging Infectious Diseases. 2006;12(4): 653-660.  
Available at: <http://www.cdc.gov/ncidod/EID/vol12no04/05-0602.htm>. Accessed 24 March 2006.

\*\*Centers for Disease Control. "Reported Lyme Disease Cases By State, 1993-2005."  
Available at: [http://www.cdc.gov/ncidod/dvbid/lyme/ld\\_rptdLymeCasesByState.htm](http://www.cdc.gov/ncidod/dvbid/lyme/ld_rptdLymeCasesByState.htm). Accessed 25 Feb 2007.

## **Written Testimony**

### **Introduction**

Over 700 patients have shared their stories at the Wilton Lyme Disease Support Group since 1998. The vast majority arrived with late-stage Lyme disease (LD) that advanced due to misdiagnosis\* or inadequate treatment. The physical and emotional suffering these patients recount can be heart-breaking. Stage 3 Lyme disease is a debilitating, multi-systemic illness that can cause neurologic, cardiac and arthritic symptoms, among others.<sup>1,2</sup> Patients' lives may be thrown into turmoil by the intensity of their illness. In addition, they may be overcome by financial burdens.

Over the years, trends have emerged in patient narratives. Their stories suggest the critical importance of assessing the economic costs associated with misdiagnosed and under-treated Lyme disease. The ramifications are not limited to patients and their families but extend to schools, employers, insurers and government. Understanding LD's true economic impact is vital in order to reduce the incidence of advanced disease and to properly allocate public funds for prevention and research.

### **Problems and Significance**

Although Lyme disease is the most common vector-borne disease in the United States, economic research has been limited.<sup>3,4</sup> Costs associated with misdiagnosis and under-treatment have received little attention.<sup>5,6</sup> On the contrary, several reports have addressed the possibility of over-diagnosis and over-treatment.<sup>7,8,9,10,11,12</sup> Ulrich Hengge and

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\* "Misdiagnosed" in this paper refers to cases in which a correct diagnosis of Lyme disease was delayed when symptoms were mistaken for another condition.

colleagues described the latter perspective in their review of LD, published by *The Lancet* in 2003:

"Extensive and often inaccurate publicity about the risk and outcomes of Lyme borreliosis has produced considerable anxiety about the disease. One result of this reaction is the inappropriate use of serological testing for Lyme borreliosis to identify the cause of widely prevalent, non-specific symptoms, such as pain and fatigue. This practice, in turn, has led to a virtual epidemic of over-diagnosis and over-treatment of patients with Lyme borreliosis."<sup>13</sup>

Physicians and policymakers who rely on this position without giving equal consideration to the burden imposed by delayed diagnosis and inadequate treatment may place citizens at risk. Anecdotal reports suggest that clinicians are influenced by the "over-diagnosed, over-treated" theory when they assess patients, decide on tests and prescribe medications. Physician decision-making is also complicated by numerous medical uncertainties regarding LD diagnosis and treatment, which have become quite controversial.<sup>14, 15</sup> While the Wilton Support Group represents a skewed sample of patients, since those who attend tend to be late-stage, their experiences are revealing. Many developed serious, preventable complications because their doctors were reluctant to consider Lyme. Consider this May 2006 e-mail from a patient seeking help:

"M. kindly gave me your name and suggested I might want to consult with you about my bout with Lyme disease. Here's my story: I was bitten by a deer tick and watched the bite closely for about 2 and a half weeks. The bite itself didn't turn into the classic bull's-eye, but neither did it go away. It itched a good bit and continued to stay active.

At about the two and a half week mark, I began to develop unmistakable flu like symptoms - aches, weakness, general malaise - but no fever. I saw my doctor whose opinion is that Lyme disease is over diagnosed, over treated and very politicized. He prescribed 200mg of doxycycline for two weeks and said it was my decision whether to take it or not.

After speaking with some Lyme disease- knowledgeable friends, however, I decided not only to take the antibiotic, but to double the dose for double the amount of time. I've been on the antibiotic now for 10 days and feeling better, but the rash around the bite is getting larger, not vanishing.

Would love to know your thoughts on this. At this point, it is my understanding that there is no definitive test to determine whether or not I have the disease and no way finally to know if I kill it, and there seems to be no agreement about how long one should take the antibiotic. Any light you can shed on the subject would be most welcome."



Although this patient had a known tick-bite, an expanding rash and flu-like symptoms, all of which point clearly to early LD,<sup>16</sup> her physician assumed Lyme was not likely based on the premise it is over-diagnosed and over-treated. He apparently did not perform a blood test and left the decision whether to take antibiotics in her hands. While it is possible he was correct and she did not have Lyme disease, it is also possible, had she followed his advice, she would have landed in the Support Group months or years later with neurologic, arthritic or other complications. Many Support Group visitors with similar histories are now struggling with a reduced quality-of-life and significant financial burdens.

It is important to note that over-diagnosis and over-treatment are real possibilities that must be taken into account for the sake of patients and society. However, considering Lyme's rapid spread through the nation,<sup>17</sup> the debilitating nature of late-stage disease,<sup>18, 19</sup> the higher costs associated with advanced illness,<sup>20, 21</sup> and the possibility that serious symptoms may persist despite standard treatment,<sup>22</sup> research is needed to assess the other side of the coin—misdiagnosis and under-treatment—so that clinicians can make balanced decisions.

The economic consequences of misdiagnosis and under-treatment have important policy implications as well. Public funding agencies such as the Centers for Disease Control (CDC) and the National Institutes of Health (NIH) need comprehensive data in order to set funding priorities for research and prevention. For example, the NIH allocates funds based on "disease burden," a complex assessment that includes the number of people affected, the number of deaths that result, the extent of disability produced, the effect on quality of life and productivity, the importance of preventing additional cases, and the economic and social expenses generated.<sup>23</sup>

Adequate funding depends on accurately assessing these factors. Costs generated by misdiagnosis and under-treatment may be hidden but highly significant (for example, delays might necessitate treatment with intravenous antibiotics rather than less expensive orals). In addition, misdiagnosis may lead to inappropriate tests and treatments that might be ineffective, harmful or expensive (for example, a misdiagnosis of Multiple Sclerosis might result in treatment with steroids, which can worsen LD and its symptoms). It is important, therefore, that funding agencies take misdiagnosis and under-treatment into consideration as they set research priorities.

### **Planned Research**

I am currently developing a survey that aims to assess in broad strokes the economic effects of misdiagnosis and under-treatment in patients with confirmed, late-stage Lyme disease. The ultimate goal is twofold: reduce the incidence of advanced disease and relieve the burden of those who are currently suffering. Toward that end, it is hoped results will:

- Educate physicians, so they make balanced clinical judgments. Diagnostic considerations should include the dangers of both over-diagnosis and misdiagnosis.
- Influence public funding agencies such as the NIH and the CDC to increase funding for prevention and research.

The survey also explores several related issues that are well-known to those living in endemic communities. For example, repeat infections are not uncommon and some individuals have been re-infected multiple times. More than one member of the household, and sometimes several, may be infected. Patients may contract other tick-borne diseases that resemble Lyme and can be co-infected with two or more pathogens from a single

tick-bite.\*<sup>24</sup> Insurance companies may deny claims, especially due to medical debates regarding laboratory testing.<sup>25</sup> School systems may feel Lyme's effects in their special education budgets.

### **Lyme Disease Symptoms**

The economic implications of misdiagnosed and under-treated Lyme disease depend on the nature of the illness. Lyme disease is caused by a spiral-shaped bacterium—a spirochete known as *Borrelia burgdorferi*—that is transmitted to humans through the bite of a deer tick. Many, but not all, patients develop a tell-tale, expanding rash (erythema migrans) that is “unique to Lyme disease.” The rash may be accompanied by flu-like symptoms such as fever, body aches, fatigue, headache and stiff neck.<sup>26</sup>

If left untreated, Lyme disease can spread throughout the body. Scientists refer to “three stages of illness (early localized disease, early disseminated disease, and persisting late disease).”<sup>27</sup> A wide variety of symptoms are possible. Arthritic afflictions may include painful, swollen joints that can “shift from one joint to another.” Knees are affected most often. Neurological symptoms may include temporary facial paralysis (or Bell's palsy), severe headache and stiff neck due to meningitis, concentration and memory impairments, and/or muscle discomfort such as weakness, numbness or pain. Cardiac issues may include irregular heartbeat, dizziness and shortness of breath. In addition, Lyme can cause symptoms as diverse as eye inflammation, hepatitis, and sleep disturbance, among others.<sup>28, 29</sup>

Lyme disease has been likened to syphilis, another spirochetal illness, because of its propensity to mimic other conditions. As the long list of symptoms outlined above makes

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\* According to the CT Agricultural Station's Tick Management Handbook, “In a Connecticut and Minnesota study, 20% of Lyme disease patients also had serological evidence of exposure to another tick-borne agent (p. 15).”

clear, Lyme might easily be confused with a host of other disorders, from spider bites to Multiple Sclerosis (MS). Many physicians believe it should be "considered in the differential diagnosis of rheumatologic and neurologic conditions, as well as chronic fatigue syndrome, fibromyalgia, somatization disorder and any difficult-to-diagnose multi-system illness."<sup>30</sup> Wilton Support Group visitors have been diagnosed with MS, arthritis, chronic fatigue syndrome, early menopause, early Alzheimer's disease, psychiatric illness and ADHD before finding relief under the care of Lyme specialists.

Indeed, the neuropsychiatric manifestations of Lyme disease cannot be overlooked, especially because they, perhaps more than other symptoms, may account for much misdiagnosis. Several studies have documented potentially disabling cognitive and psychiatric disorders resulting from Lyme in both adults and children, including depression and ADHD.<sup>31, 32</sup>

In 2002, the *American Journal of Psychiatry* published a study in which approximately 900 patients from the Prague Psychiatric Center were tested for Lyme disease, as were approximately 900 controls. Subjects were then matched by age and gender. Among the matched pairs, 33% percent of the psychiatric patients had positive blood tests, versus 19% of the controls. This study implied a causal link between Lyme disease and psychiatric illness<sup>33</sup> and was also a dramatic illustration of the potentially tragic, unnecessarily expensive consequences of misdiagnosis.

### **Lyme Disease Diagnosis**

Diagnosing Lyme disease may be difficult. The process is complicated by several factors. As noted above, symptoms may well resemble those of numerous other conditions (including several tick-borne illnesses). In addition, a single tick may co-infect patients with

two or more pathogens. Perhaps most importantly, commonly used lab tests are not conclusive.<sup>34, 35</sup>

The erythema migrans rash unique to Lyme disease is the best diagnostic marker available. However, it is “absent in at least one-fourth of the people who become infected”<sup>36</sup> and possibly more. In addition, it may well be missed<sup>37</sup> (especially if it presents on the back or scalp<sup>38</sup>). It can also assume an atypical form,<sup>39</sup> increasing the chances it will be misdiagnosed as another skin condition.

Without the rash, what difficulties do patients encounter in the diagnostic process? According to Brian Fallon, MD, MPH, M.Ed. (Associate professor of clinical psychiatry, Columbia University, and Director, Lyme Disease Research Program, New York State Psychiatric Institute), Lyme’s multi-systemic nature may be problematic when patients visit specialists, who tend to concentrate on symptoms that fall within their realm of expertise. Dr. Fallon described this phenomenon in a 2003 interview, stating that patients with multiple complaints may struggle to find a physician who recognizes a possible interrelationship, thus postponing the proper diagnosis (and engendering multiple, costly visits). Also, such patients take time to evaluate. Insurance constraints may leave clinicians little opportunity to unravel a complex medical mystery.<sup>40</sup>

The NIH states the “Lyme disease bacterium is difficult to find in laboratory tests of body tissues or fluids.”<sup>41</sup> Indeed, testing for the illness is the subject of intense debate.<sup>42</sup> The NIH is supporting research to improve its accuracy<sup>43</sup> but until tests are perfected, assessing both infection and cure will likely remain problematic.

At the moment, doctors rely most often on antibody tests, such as the ELISA and Western Blot, which measure the body’s response to an infection. However, these may not be

correct, especially in the weeks immediately following infection, since antibodies need time to develop. The tests are also affected by antibiotics,<sup>44</sup> diverse immune system responses, and bacterial strain variations.<sup>45</sup>

Results may vary from lab to lab. Dr. Fallon notes a single blood sample may be positive according to one lab, but negative according to another—a phenomenon he says has been studied by the NIH but is not widely known by doctors.<sup>46</sup>

The CDC recommends two stages for testing. The ELISA comes first; if results are positive or equivocal, the Western Blot (a more expensive test) is next.<sup>47</sup> But does the ELISA have the sensitivity needed for screening? Some experts assert a significant number of patients are negative on the ELISA but positive on the Western Blot.<sup>48</sup> Interpretation of the Western Blot is also problematic. The CDC has established a standard that is debated by researchers and laboratory directors. Dr. Fallon thinks these disputes, too, are unfamiliar to many physicians.<sup>49, 50</sup>

According to both the CDC<sup>51</sup> and the NIH, Lyme should be diagnosed on the basis of clinical symptoms. Lab tests may support the doctor's conclusions, but should not decide the matter. Clinicians are encouraged to rely on their "judgment," taking into consideration "time of year, history of tick bite, symptoms" and other possible illnesses.<sup>52</sup> Nevertheless, Dr. Fallon and Wilton Support Group leaders have seen doctors rely exclusively on negative results from one lab, even with clear-cut clinical evidence (such as Bell's palsy) to the contrary. Subjective symptoms like fatigue and sleep disturbance are even more problematic and, without a definitive test, can be easily ascribed to depression and other illnesses.<sup>53</sup>

Thus, Lyme's propensity to mimic other conditions, the proliferation of additional tick-borne infections, healthcare trends, and inconclusive lab testing all contribute to the possibility of misdiagnosis and delayed treatment.

### **Impact of Delayed Treatment or Under-treatment on Quality-of-Life**

Why are misdiagnosis, delays, and under-treatment important? Experts agree delays may lead to multi-systemic symptoms<sup>54, 55, 56</sup> but treating these complications is another source of controversy. According to the NIH, "the sooner treatment is begun following infection, the quicker and more complete the recovery."<sup>57</sup> Most patients (about 90%, according to some studies<sup>58</sup>) with the characteristic rash respond well to recommended antibiotic treatments. Eradicating disseminated Lyme takes more effort and is hotly debated.<sup>59, 60</sup>

In particular, patients who fail to respond to standard antibiotic doses challenge physicians, since the nature of ongoing symptoms has provoked contradictory interpretations. Some researchers believe persistent problems are caused by an active infection.<sup>61</sup> Others theorize they represent an immune or inflammatory response to an infection that has been cured. The NIH reports some patients may be "genetically predisposed to develop an autoimmune response that contributes to their symptoms" and is exploring this possibility with further research.<sup>62</sup>

Two very different sets of evidence-based treatment guidelines have been accepted by the National Guideline Clearinghouse. The Infectious Diseases Society of America (IDSA) issued its original guidelines in 2000, stating "Response to treatment is usually slow and may be incomplete. However, unless relapse is shown by reliable objective measures, repeat treatment is not recommended."<sup>63</sup> (The guidelines were updated in 2006, but the advice is the

same.<sup>64</sup>) Conversely, the International Lyme and Associated Diseases Society (ILADS) issued its own guidelines in 2004. Its web site states: “A preponderance of evidence indicates that active ongoing spirochetal infection...is the cause of persistent symptoms in chronic Lyme disease....There has never been a study demonstrating that 30 days of antibiotic treatment cures Lyme disease....Most cases of chronic Lyme disease require an extended course of antibiotic therapy to achieve symptomatic relief.”<sup>65</sup>

Treatment costs depend on antibiotics utilized and duration of therapy (as well as other medications and methods that may provide relief), so this debate has significant economic implications. Until science ends the uncertainty with definitive proof, costs will vary according to the beliefs and practices of treating physicians (and insurers). However, despite pronounced differences regarding the cause of persistent symptoms and treatment methods, experts from both camps agree patients with chronic Lyme disease truly suffer—their quality-of-life is profoundly reduced.

For example, in 2001, researchers at Tufts University, investigating 129 patients with “well-documented Lyme” and “symptoms that persist after recommended antibiotic treatment” found that the “effect of chronic Lyme disease was substantial....The deficits in physical health status as measured by the SF-36 were equivalent to those in patients with congestive heart failure or osteoarthritis and were more than 0.5 greater than impairment observed in patients with Type 2 diabetes or a recent myocardial infarction.” Chronic pain and profound fatigue were major culprits. The study also documented serious psychiatric and cognitive impairments.<sup>66</sup>



These significant physical and mental effects, whether treated with antibiotics or other methods, are expensive to endure long-term, as visitors to the Wilton Support Group have reported again and again.

### **Lyme Disease Incidence and Prevalence**

The economic impact of misdiagnosed and under-treated Lyme disease depends not only on the extent to which patients' lives are compromised, but also on the frequency with which these phenomena occur.

Reported Lyme disease incidence nearly doubled from 1991 to 2000<sup>67</sup> and rose 40% from 2001 to 2002,<sup>68</sup> despite federal, state and local attempts at control and prevention.<sup>69</sup> Experts acknowledge that reported cases do not adequately reflect the extent of Lyme's reach. During the 1990s, studies suggested that LD cases were "under-reported by six to 12 fold" in some endemic communities. Under-reporting rates have not been studied recently and therefore current trends are unknown. States vary in their reporting requirements, further complicating data collection and assessment.<sup>70</sup>

In Connecticut (CT) (which as of 2002 had the highest incidence of Lyme in the nation), the CT Agricultural Experiment Station estimates that "the number of Lyme disease cases reported may represent only 10-20% of diagnosed cases."<sup>71</sup> Today, the low percentage of CT physicians reporting has crucial implications not only for the State but for the nation (which relies on states to report), because in January 2003, CT eliminated mandatory laboratory reporting.<sup>72</sup> Since then, CT case reports have dropped dramatically, from 4,631 cases in 2002 to 1,403 cases in 2003.<sup>73</sup> Unless reporting methods are standardized across the country, and include mandatory reporting by both physicians and labs, Lyme's true incidence is open to serious question.

A number of surveys have been conducted by the CDC and local communities in CT that shed light on the magnitude of the epidemic. One such survey, conducted in 2001 by Millward Brown (then the largest worldwide supplier of consumer research) surveyed three CT towns: Newtown, Ridgefield and Wilton. Four hundred households were targeted for random calls in each town, with a total sample of 1200. The survey found that "39% of households have some member who has been diagnosed with Lyme disease" or 17% of the population. The majority of those diagnosed had a positive blood test (64%) or a bull's eye rash (66%). Virtually all of these cases were treated with antibiotics. Despite treatment, results indicated that 5% of the towns' total populations suffered "lingering symptoms."<sup>74</sup>

Since the combined population of these towns in the year 2000 was 66,307,<sup>75</sup> approximately 11,272 residents were therefore diagnosed with Lyme disease at some point prior to 2001. Of these, about 3315 people continued to experience symptoms despite antibiotic treatment. Approximately half of diagnosed cases occurred between 1998 and the time of the survey, in early 2001,<sup>76</sup> which translates to 5523 cases of diagnosed Lyme disease in that time period.

Contrast these numbers with cases reported to the State by doctors and laboratories between January 1998 and December 2001. Total reported cases for these three towns amounted to 811 (verses 5523 per Millward Brown), which include case reports submitted in the latter half of 2001, well after the survey was completed. The difference is seven-fold, and therefore in line with CDC and Connecticut estimates about under-reporting.<sup>77</sup>

The scientific literature generally refers to a "small percentage" of patients who experience symptoms after "appropriate" treatment,<sup>78</sup> however, this survey found that 23% of those with diagnosed Lyme had lingering symptoms.<sup>79</sup> There is thus a demonstrable,

significant disconnect that exists between residents' experience, official government case numbers and the scientific literature. (In CT, this disconnect may have grown since the elimination of mandatory laboratory reporting in 2003.)

Of note, a survey conducted by the Town of Wilton in 2002 found that 54% of households were affected,<sup>80</sup> versus 44% in Wilton per Millward Brown the year before,<sup>81</sup> suggesting an increase in cases consistent with national incidence rates (a rise of 40% between 2001 and 2002).<sup>82</sup>

LD risk can also be assessed by determining the number of deer in a community (the more deer, the more ticks<sup>83</sup>), as well as the percentage of ticks infected. In Wilton's Weir Preserve, for example, aerial surveys conducted in 2002 found 79 deer per square mile.<sup>84</sup> Suburban communities along the CT coastline typically have 30 to 40 deer per square mile. Reducing Lyme disease incidence requires deer densities of 8 per square mile or less.<sup>85</sup> About 30% of ticks in Wilton are infected with Lyme.<sup>86</sup>

Physicians making clinical judgments on the probability of Lyme in their patients need to be aware of acknowledged inadequacies in reporting, as well as alternative methods to assess incidence and risk, in order to properly diagnose their patients, thus reducing the effects and costs of advanced LD. Without such knowledge, and as long as the "over-diagnosed, over-treated theory" predominates the scientific literature, patients are at increased risk for misdiagnosis and delayed treatment.

### **Economic Research to Date**

The Centers for Disease Control and Prevention (CDC) recently issued a report estimating LD's economic impact on Maryland's Eastern Shore, a 4-year study that was initiated because economic information on Lyme has been limited.<sup>87</sup> The authors stated

“previous studies...were often based on numerous assumptions and experts’ suggestions....Only a few studies provided costs estimates of LD based on data collected from the field....Even in those studies, however, cost estimates only related to direct medical charges or certain diagnosis or treatment procedures....This study more comprehensively documents the economic impact of LD from a societal perspective.” However, the researchers found that costs declined over the study period, a finding they could not explain.<sup>88</sup> They did not explore several issues that the attached survey will investigate, such as repeat infection, co-infection, number of household members affected, and insurance claim denials.

As mentioned earlier, several studies and reports suggest that Lyme disease is over-diagnosed and over-treated, resulting in “excessive utilization” and “unnecessary use” of health services. Researchers have concluded that anxiety regarding Lyme disease played a role. Depression and stress are also cited.<sup>89, 90</sup> However, other studies suggest that Lyme disease may be under-diagnosed; indeed, it may well be responsible for psychiatric symptoms in some patients.<sup>91, 92</sup> Inadequate treatment has also been associated with relapse and debilitating symptoms.<sup>93</sup> It seems potential costs to society through misdiagnosis and under-treatment, while acknowledged,<sup>94, 95</sup> have not been fully investigated.

In 1999, the CDC issued recommendations regarding the Lyme disease vaccine that were based on two studies. The Maes study provided a societal perspective, while the Meltzer study considered the third party payer point of view. In general, the CDC found that the expense of the vaccine was justified only in highly endemic communities or for individuals at especially significant risk. However, “the likelihood of early diagnosis and treatment also had a substantial impact on vaccine cost effectiveness.”<sup>96, 97, 98</sup>

The Maes study, entitled "A Cost-of-Illness Study of Lyme Disease in the United States," described the complexities of assessing Lyme disease costs. Since Lyme "produces a diverse clinical picture that can include serious and potentially debilitating cardiac, neurologic, joint and skin involvement," and since the illness has three stages, costs will vary depending on the stage of illness and the physician's understanding of options. Furthermore, reported incidence, problems with serologic testing, missed rashes, over-diagnosis, under-diagnosis and misdiagnosis were all cited as confounding factors that led the authors to develop a conservative model. The researchers specifically stated that "We have not included in the model the costs of diagnostic testing and treatment when a physician misdiagnoses Lyme disease for one of these conditions (i.e. meningitis, multiple sclerosis, lupus or rheumatoid arthritis), because these costs are not well captured."<sup>99</sup>

Using this conservative model, the authors found that the U.S. might spend "\$2.5 billion for the prevention of 55,626 cases of Lyme disease sequelae over a 5 year period, at a yearly mean incidence of 4.73 per 100,000 population." Existing research pointed to "substantial" diagnostic and treatment expenditures. Additional research regarding short and long term morbidity and medical costs was urged.<sup>100</sup>

The authors measured the costs of medical services, medications, days of limited activity, and lost productivity at work and school not by analyzing actual Lyme disease cases, but by estimating the costs of similar symptoms that have been documented for other conditions. Symptoms included flu-like, cardiac, musculoskeletal, neurologic, dermatologic and other manifestations. An expert panel was convened to "make judgments about the development of the manifestations and sequelae." Probabilities were assessed according to disease stage based on the experiences of the panel. Estimates of health care utilization were

obtained from the National Interview Health Survey, which did not at the time collect data specific to Lyme disease. The use of estimates and probabilities points to the need for further research based on actual experience with Lyme disease.

Applying the Maes results to the Millward Brown respondents provides a crude estimate for at least a few costs incurred in three specific towns. For example, if we average the Maes estimates for lost productivity by symptom (Table II), the mean value of lost time per adult is \$1360. Multiply this figure by the number of people in the three towns with lingering symptoms--3315--and the result is \$4,508,400. This is not a precise measure, however, since the 3315 figure is not broken down by adults and children and it is impossible to know what types of symptoms were commonly found in the sample. If we average the mean annual costs for adults with stage two and three symptoms (Table IV), the result is \$3943. Multiply this figure by 3315 and the result is \$13,071,045. Again, this provides a very crude clue into possible costs because the data were difficult to compare precisely and because the Maes figures are not based on Lyme patients' actual experiences.

As mentioned above, the 2006 CDC report, entitled "The Economic Impact of Lyme Disease," notes the limitations of the Maes study and others that relied on "assumptions and experts' suggestions." The current study found that costs declined during the study period, which lasted 4 years (a phenomenon that might shock Wilton Support Group visitors). The researchers were unable to determine the cause of the decrease. They conclude by stating that "LD is the most common vector-borne zoonotic inflammatory disease in the United States....The long-term sequelae of LD are debilitating to patients and costly to society....The emergence of LD and previous experience predict the feasibility of public

health interventions for LD control and prevention....More research on the social behavior of LD patients and economic evaluation of LD prevention interventions is needed.”<sup>101</sup>

### **Practice and Policy Implications**

Economic issues relating to Lyme disease need to be studied in more patients and in more depth in order to address the needs of thousands of residents in endemic communities who either suffer with lingering symptoms or face increasing risks as Lyme disease spreads across the nation. Newly emerging tick-borne diseases complicate the matter and yet may be responsible for many unanswered questions regarding persistent symptoms and testing.

Anecdotal reports suggest that those in high risk areas may be infected more than once. In addition, multiple family members may be affected, causing additional, complex economic hardships. The frequency of this phenomenon has not been documented but should be, since the burden of medical bills, lost work/school days, care-giving and stress associated with chronic illness would be that much greater when several family members are suffering.

In particular, attention must be paid to the economic ramifications of misdiagnosis and under-treatment, in order to insure clinicians will make balanced judgments when diagnosing patients according to CDC criteria in endemic areas. Considering the breadth of the epidemic, the debilitating and even disabling nature of late-stage illness, the costs—both hidden and obvious—associated with advanced disease, and the possibility symptoms will remain despite standard treatment, the implications of misdiagnosis and under-treatment have far-reaching consequences. Public funds for research and prevention need to reflect these phenomena.

Until researchers determine with certainty the cause of persistent, late-stage Lyme disease and the best methods for treatment, patients will continue to battle symptoms that

affect not only their personal well-being, but the financial security of their families and the economic fabric of their towns and states. The respondents in the Millward Brown survey all had the benefit of CDC and private advocacy prevention efforts. Nonetheless, rates of Lyme disease in these communities, and rates of lingering symptoms, were extraordinarily high. Hundreds of patients seen at the Wilton Lyme Disease Support Group testify to the importance of this research.



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